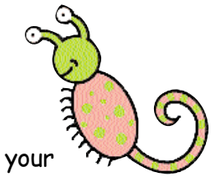
Your new baby is special!



The Michigan Department of Community Health wants to help your baby get an early start on the road to good health. When your baby is only a few days old, important steps are taken to detect seven rare disorders before there is any sign of illness. These disorders are clinically invisible in newborns but can cause mental retardation or other serious problems if not detected early. A simple blood test during the first few days of life assures early detection and prompt treatment if needed. That is why the Michigan Department of Community Health tests every baby born in Michigan.

What is Newborn Screening?

Using just a few drops of your baby's blood, the Michigan Department of Community Health laboratory performs screening tests to check your baby for seven disorders.
They are:

- phenylketonuria (also called PKU)
- maple syrup urine disease (also called MSUD)
- galactosemia
- biotinidase deficiency
- hypothyroidism
- congenital adrenal hyperplasia (also called CAH)
- sickle cell anemia

Babies who have positive screening tests are followed up by further testing or referral to medical specialists. Each year at least 150 Michigan babies are diagnosed and referred for treatment by the Newborn Screening Program.

What are the seven disorders?

1. **PHENYLKETONURIA (PKU)** is an inherited disorder in which the baby is unable to use a certain part of protein in food and milk. It accumulates excessively to cause mental retardation unless treated with a special diet. Without newborn screening, babies with PKU may go undetected for months or years until mental impairment is obvious.

2. **MAPLE SYRUP URINE DISEASE (MSUD)** is a rare inherited disorder in which the baby is unable to use parts of protein in food and milk. Without newborn screening, babies with MSUD may become seriously ill and die before detection. The treatment for MSUD is a special diet.

3. **GALACTOSEMIA** is an inherited disorder that prevents the baby from digesting a certain kind of sugar (galactose) found in foods such as breast milk and all infant formulas except soy. Without newborn screening, babies with undiagnosed galactosemia can develop jaundice (yellow skin color), become ill very quickly and die within the first two weeks of life. The treatment for galactosemia is to replace milk products in the diet with a milk substitute.

4. **BIOTINIDASE DEFICIENCY** is an inherited disorder in which the baby is unable to use a necessary vitamin called biotin. Biotin is important in the metabolism of all foods. Without newborn screening, babies with biotinidase deficiency may not be detected for weeks or even years until convulsions or mental retardation occur. The treatment for this deficiency is additional biotin in the diet.

5. **SICKLE CELL ANEMIA** is an inherited disorder (more common in babies of African-American parents) that affects the baby's red blood cells. Without newborn screening, some babies with sickle cell anemia may not be detected early enough to prevent sudden death from infection. Daily penicillin is the treatment to prevent such infections and other medical care can be provided as needed.

6. **HYPOTHYROIDISM** is a disorder in which the baby has a low level of thyroid hormones. Without newborn screening, babies with hypothyroidism may not be detected until mental retardation or poor growth occurs. The treatment for hypothyroidism is regular thyroid hormone replacement.

7. **CONGENITAL ADRENAL HYPERPLASIA (CAH)** is an inherited disorder that affects the baby's adrenal gland hormones. Without newborn screening, babies with CAH may become ill and die before a diagnosis can be made. It also causes poor growth if left untreated. The treatment includes adrenal hormone replacement.

What happens if one of the tests is positive (abnormal)?

A positive screening test does not necessarily mean your baby has one of the seven disorders. In fact, many babies have a slightly positive first screen for a variety of reasons. If so, a second test is required. Any baby whose screening test suggests a high chance of having one of the disorders will be referred to a medical specialist for confirmation of the diagnosis and treatment. The Michigan Department of Community Health will notify your baby's health care provider who will contact you with instructions for follow-up.

If my baby has one of these disorders, is there a cure?

Babies with these disorders cannot be cured, just as eye color or blood type cannot be permanently changed. However, the serious effects of these disorders can be greatly reduced or completely prevented if a special diet or other medical treatments are started early. Most children grow and develop normally when early diagnosis is followed by appropriate medical care.

My baby seems healthy. Are screening tests really necessary?

Absolutely. Experience has shown that newborn screening is the only reliable method of finding babies with these disorders early enough to prevent mental retardation or early death. Since most babies with these disorders appear healthy at birth, the special screening tests can identify these problems before a baby gets sick.

When should my baby be tested?

Be sure your baby is tested before you leave the hospital. If this is before 24 hours of age, a second test is recommended within the first week of life. Your baby's health care provider will be notified of test results.

What happens to my baby's blood specimen after testing?

Newborn screening specimens are kept by the department for 21.5 years and then destroyed. During this time, some specimens may be used for medical research. Before any medical research is conducted, all identifying information is removed from the blood specimen card to protect privacy. If you have any questions or concerns, please contact the Newborn Screening Program.

Can the blood specimen be returned to me following testing?

No, however the state law provides you with the option of asking that a second specimen be obtained at the same time as the newborn screening specimen. You can keep this specimen at home with your baby's records or in another safe place. This second specimen may be important to your family at a later date for identification purposes.

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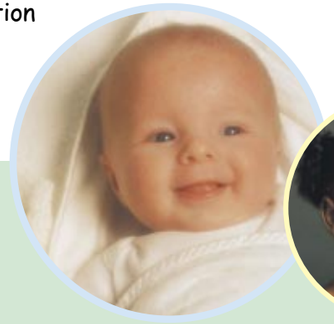

Is there anything I need to do?

Make sure your baby is tested. Ask your doctor or hospital staff if a specimen was obtained for newborn screening and sent to the Michigan Department of Community Health Laboratory for testing.

If your baby is discharged from the hospital before 24 hours of age, take your baby to your health care provider for a retest within one week.

Ask your health care provider for your baby's newborn screening test results.

Follow your doctor's recommendations for any additional tests or medical appointments.

Any other questions?

Please talk to your health care provider, or call or write us at:

Michigan Department of Community Health
Newborn Screening Program
3423 N. Martin L. King Jr. Blvd.
P.O. Box 30195, Lansing, MI 48909

Phone: (517) 335-9205
Fax: (517) 335-9419

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Your Baby and Newborn Screening

Notice: All babies born in Michigan will now be tested for EIGHT disorders.

The Michigan Department of Community Health is pleased to announce the addition of Medium-Chain Acyl-Coenzyme A Dehydrogenase (MCAD) Deficiency to the newborn screening panel. As of April 1, 2003, all babies born in Michigan will be tested for MCAD Deficiency.

8. MCAD DEFICIENCY is an inherited disorder that interferes with the body's ability to use fat as an energy source when sugars are not available. This may occur after vigorous exercise, missing a meal or when fighting a simple infection like stomach and intestinal flu. Without newborn screening, babies with MCAD deficiency might suffer seizures, coma, or even sudden death. The treatment for MCAD deficiency involves dietary modifications and a special emergency plan for times of illness.

70,000 copies printed at $0.015 each with a total cost of $1,096.76

REMEMBER:

- Without screening, there is no way to tell if your baby has one of these disorders. Even affected babies appear normal at birth.
- Do not leave the hospital before your baby has the newborn screening test.
- Early diagnosis, treatment, or other interventions can prevent mental retardation, disability and/or death.
- Check with your pediatric health care provider about your baby's newborn screening results.